

Carolyn's Story

Carolyn wrote her own story.

My name is Carolyn Cordon. About a year ago, in fact in late February last year (2010), I had a bit of a collapse, and eventually the doctors decided what I had was Multiple Sclerosis (MS).

It was a bit of a wake-up call, things are different now, but it's not as bad as I thought it would be, because I was thinking "brain tumour". Multiple Sclerosis is much easier to deal with than a brain tumour. My husband and I have a friend who's had Multiple Sclerosis for as long as we've known her, and she's still going. She's not as mobile as she used to be, but she's still able to do what she wants to do. So, we thought, "Yes, this is something we can live with". And we've been living with it.

MS has certainly slowed me down. My ability to go for long walks is gone—literally. I can't see myself going hiking the way my husband, my son and I used to. I'm not walking the dogs at all, but I can get up out of bed and walk. I'm still living at home. My husband has a full time job which pays him very well, and he also gets a carer's allowance. He's been very good; he's doing all of the things, the housework type things that I'm no longer able to do.

I think it is very wonderful to have a supportive family and if I didn't have my husband, Graham, life would be much more difficult. If I can't do things, it doesn't matter because I know they will get done, if they have to get done. But I have also rationalised things that do actually have to get done. You realise the difference between *needing* and *wanting* things done.

I *want* to have a healthy house to live in, and I *want* to have a tidy house. I *need* to have a house that's tidy enough to be healthy. If you come into my bedroom where I am at the moment folding clothes, it's not particularly tidy, but it doesn't matter because I'm aware of all of the trip hazards that are there and I walk very carefully. The rest of the house is as tidy as it has to be.

With regards to MS, there has been some restriction of what I used to do before and cannot do now. For instance, I used to go once a week to the Central Markets in Adelaide and do our fruit and vegetable shopping and get the little lovely bits and pieces that you get.

During summer, I wasn't able to do that because I was too fatigued. And I haven't started doing it again as yet. My husband and I are both hoping that I will be able to go back to doing that, but at this point in time, I don't feel well enough to do that. And over time I've learnt that my body knows a lot more than my brain knows about what I can and can't do. If my body's saying "No, you can't do that Carolyn," I listen,

because I do have this slight fear of being out doing something, and collapsing and not being able to get up again.

But gradually I've discovered that I am a very special person, because I'm coping very well with what I'm learning about myself, and I certainly know other people who are not coping at all well. I'm a very placid sort of person, and I'm also a person who lives a lot of their time in their head. I've always been like that; I'm a writer, I'm a poet. My thinking is very important.

I can quite happily sit out on our front veranda and watch the birds and the clouds and the insects. I could do that for as long as I want, an hour, longer even. It's like there are people who sort of *have* to be up and doing things. But I'm not that sort of person and that's why I've been able to write something which is humorous, but also true—it was ten reasons why MS was the best disease for me to get. I posted it [online](#) and I earned a tiny bit of money from it.

I've used my creative writing as a personal therapy to get me get through this. I've had a few issues through my life, as everybody does, and my personal writing has helped me to come to terms with things a lot better than perhaps people who don't do any journaling or personal writing. I'm healing myself with my own words.

I'm not the sort of person who worries. I've got lots of thoughts on worrying. Worrying is the most unproductive thing. All it does is makes you unhappy and I want to die with people saying, "Gee, she was always such a happy person". And they might say, "God, she kept a very untidy house though," but they'll remember the happiness more than the untidiness.

My family has been very supportive. I've got one 17-year-old son. His name is Jake. He's on holidays at the moment, and he's a wonderful help. He complains, as 17-year-old sons do, when I ask him to do something, but today he's hung out the washing, and brought it back in again. I think he is aware of the type of support I need. If I ask him to feed the dogs—we've got 4 dogs—that takes a little bit of feeding and cleaning up after. But that's okay; he does it.

For me coming to terms with MS was not too hard because I think that I'm comfortable living in my own head. I think things through, I decide what's actually best for me and my body, and what I want in life, and I'm able to go on doing the things that are most important to me.

I didn't have a paid job previously, although I have had before, but having a job isn't my most important thing. I'm a volunteer and most of my volunteer work involves poetry. Poetry is the most important thing to me; poetry and family. I'm also the editor of a newsletter for our local community of Mallala, the Mallala Crossroad Chronicle is its name, and it comes out once a month. That's my job. Basically it's a

volunteer job, but people say, “Oh, I really enjoyed this issue,” and that sort of thing—it’s most important to me that people are enjoying what I’m putting out there.

For people living with a similar situation what I would say to them is to make as many connections as you can with people who are able to help you.

When you’ve got friends, and if you have something like MS or any other sort of disability, you might lose some friends, because a lot of people don’t understand that your disease isn’t the end of your world, it’s just a bit of a hill to get over. And you might lose those people, but if you think sensibly about it, you’ll realise that losing those people is not harming you at all, because they were dragging you down. If they weren’t able to move on with you, then you’re better off without them.

But that’s why it’s important to make other connections. I’m on the computer—far too much my husband and son both say—but the computer is able to give me connections with people who have MS, who are living with MS, who have been living with MS successfully for a lot longer than what I am. And I learnt a lot from reading their stories.

A new connection for me, which has been really wonderful, is the [MS Society’s Peer Support Network](#). I’m a member of a group that’s just started up in the Gawler area, there’s five or six of us and we get together as often as we can, about once a month, and it’s just a lovely place to go and chat and learn things. I think people who have lived with the disease for longer than we have are our greatest teachers.

When I was first diagnosed with MS, I was a lot less able than what I am right now to do certain things. I was not very good at doing things with my hands, and one of the things that was driving me mad (if you’re a woman you’ll understand why this is important) was the inability to actually do up my bra.

I had a visit from an occupational therapist (again, a connection) who realised I needed help because of people I knew in [Lower North Health](#). They sent her to see me, and she was able to say, “Well, when I did my shoulder playing netball I did this—you turn your bra around the other way, and you put it on back to front, and then you turn it back the other way, and then you put your arms in!” So I thought, “Yeah! I can do the damn thing up!” And those little, *little things*, just to help you do everyday things like being able to dress yourself, are very empowering.

Apart from your connections, I think try to continue with your life the way you want it to be. Having an illness like this is a great opportunity to rethink what you really, truly do want in life, and you realise that having the perfect home is not as important as having wonderful friends and your family around. Perhaps see the best in what you have, but think about what it is that you really, truly do want in life, and do

everything you can to live the best life you can for yourself. Thus the bottom line is: “Prioritising your life is very important”.

MS is another hill in my journey, but it’s not a hill that’s going to stop me. It’s going to make me think more deeply about what it is that I want, it’s a hill that’s being flattened out by my understanding of what it is I truly want, and I think the longer I live with it, the more I’m going to realise that it wasn’t really a hill at all, it was just a bit of a slope.

I feel it’s a bit of a window of opportunity because at the moment I’m working on putting a poetry collection together, and that’s on its way, it’s nearly finished, and once that’s been launched, and talked about, then I go onto my next project, which is going to be writing a non-fiction book about my MS journey. So you see, I have goals in my life, and they’re goals that suit me and the new life I’ve been given. So I’m not looking on my MS as being a ruined life, I’m looking on my MS as being new opportunities and new ways of thinking.

So, what I am good at is looking at my life and seeing things in a good way. If I can’t say, “Yep, it’s been a good day today,” every single day, then I’m not looking properly. There’s no point worrying about what I won’t be able to do tomorrow.

I strongly agree with what the interviewer mentioned to me, that sometimes “we worry too much about things beforehand, and then it’s better just to deal with them when they come along”. I realise that it may well happen, and one of the things that struck me, because so many people kept saying it, experts in MS kept saying “use it or lose it”, and I’ve started on a bit of exercise classes at Elizabeth South with the MS Society, and I’ll be going back there again next month.

One thing I started doing was exercises with my Wii Fit, I’ve had it for ages and ages, and I didn’t use it very often, but late last year, before Christmas, I thought, “I can do this”. So I started, I gave myself an exercise program, and I started out doing things that I thought would probably be useful for somebody with MS issues—like the balancing and that sort of stuff.

So I started doing a bit there, and I gave myself a challenge, and I said, “Okay, get it up to 30 minutes a day, and see if you can stick at that.” So, it took me a while to get up to 30 minutes every day, but I get up now, go to the toilet, get dressed, do my 30 minutes of Wii Fit—before I have breakfast, certainly before I turn the computer on—because as soon as I turn the computer on, that’s half the day gone.

I know myself; I know that if I can do it before anything else, the exercise will happen. It’s not easy, and if I don’t do it for a day for whatever reason, then I know that it’s going to be harder the next day, but I still do it.

I'm on Facebook on the computer, and I've got lots of Facebook friends and I'm involved with Facebook MS people all over the world (which is wonderful to connect with people). And one thing that kept me focused on doing exercise was I've got new friends all over the world who have MS, and to see that, yes, our health system is not really good, but it's a lot better than the US health system. These people who aren't very well off are people who haven't worked and live in America, and they're absolutely stuffed, because their health system is awful. I pay \$5.60 for my medicine every month, and they're paying thousands. It's terrible!

However I am quite proud of myself for sticking to my exercise program, but every morning after I've done my Wii Fit, and give away Wii Fit minutes that I've done and how it went, people on my Facebook page have said to me, "I'm so proud of you, well done, you've inspired me". And to have people tell me that I'm inspirational is a wonderful thing. It really, really gives me a boost, and that's one reason why I have to keep at it because I don't want to disappoint everybody and myself, so I'm proud of myself for doing that. And I will be really grateful if my story could be inspirational for other people.

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